

IABDB
Annual
Report

Fiscal Year

2009-

2011



I A B D B

The Illinois Advisory Board for Services for Persons Who are Deaf-Blind (IABDB) is committed to partnering with key stakeholders to impact positive change for all individuals who are deaf-blind and ensure they are provided equal access to resources and opportunities to lead fulfilling lives.

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I. Letter to Governor Quinn

Illinois Advisory Board for Deaf Blind

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Board Members

ISBE Representative

Dr. Laura Frankiewicz

*Governor's Office Senior Citizen
Representative*

Catherine Klein

*Governor's Office Consumer
Representative*

Geraldine Lawhorn

DCFS Parent Representative

Faye Manaster

DCFS Representative

Marsha Northrup

DHS/DDD Representative

Gail Olson

DHS/DRS Representative

Robert Griffith

ISBE Parent Representative

Roseann Slaght

*Governor's Office Parent
Representative*

Faith Rosenshein Young

DHS/DDD Parent Representative

Jody Wolfe

DHS/DRS Parent Representative

Maria Roeters

Dear Governor Quinn:

We are pleased to present this annual report of the Illinois Advisory Board for Persons who are Deaf-Blind. The report contains a summary of the Advisory Board's activities, our recommendations and our goals and objectives for the current year.

We continue to vigorously pursue our board's charge which includes providing "advice to the State Superintendent of Education, the Governor, and the General assembly on all matters pertaining to policy concerning persons who are deaf-blind, including the implementation of legislation enacted on their behalf." (105 ILCS 5/14-11.02). One of our strengths is the commitment and energy of our board members. We commend them for their efforts on behalf of Illinois' deaf-blind citizens. Further, we extend our thanks to the Governor's staff who have supported our board and facilitated the appointment of renew board members in a timely manner.

We continue to pursue our charge in the face of many serious challenges including the state's continuing economic crisis which impacts all aspects of life for persons who are deaf blind including education, vocational supports and living supports. Last year, we expressed optimism about the state's ability to respond to the needs of some of its most vulnerable citizens. Based on recent legislative actions, our optimism has faded to grave concern. While we understand the gravity of Illinois' financial situation, we will continue to advocate strenuously for services for Illinois citizens with deaf-blindness so that they may pursue a full and rewarding life in the great State of Illinois.

We appreciate your attention to our annual report and we look forward to continuing dialog towards the realization of the recommendation contained herein.

Sincerely,

Laura Frankiewicz, Ed.D.
On behalf of the IABDB

The Honorable Pat Quinn
Governor, State of Illinois

II. History, Authority and Purpose of the Board

The Illinois Advisory Board for Services for Persons who are Deaf-Blind was established in 1975 by Public Act 79-966. The Board provides advice to the State Superintendent of Education, the Governor, and the General Assembly on all matters pertaining to policy concerning persons who are deaf-blind, including the implementation of legislation enacted on their behalf.

The Board makes recommendations pertaining to, but not limited to, the following matters:

- Existing and proposed programs of all State agencies that provide services for persons who are deaf-blind;
- The state programs and financial plan for deafblind services and the system of priorities to be developed by the State Board of Education;
- Standards for services in facilities serving persons who are deaf-blind;
- Standards and rates for State payments for any services purchased for persons who are deaf-blind;
- Services and research activities in the field of deaf blindness, including evaluation of services, and;
- Planning of personnel preparation, both pre-service and in-service.

III. Introduction

When hearing the term, deaf-blind, many think immediately of Helen Keller. While Helen Keller is certainly one of the best known persons with deaf-blindness, the reality is much different. In fact, deaf-blindness is a condition which can involve a broad range of combined sensory impairments.

A person who is deaf-blind will experience the world in a unique manner. For people who can see and hear, the world extends outward as far as his or her eyes and ears can reach. For the individual who is deaf-blind, the world is much narrower. If the individual is profoundly deaf and totally blind, his or her experience of the world extends only as far as the fingertips can reach. If an individual who is deaf-blind has some usable vision and/or hearing, as many do, her/his world will be enlarged. Many individuals called deaf-blind have enough vision to be able to move about in their environments, recognize familiar people, see sign language at close distances, and perhaps read large print. Others have sufficient hearing to recognize familiar sounds, understand some speech, or develop speech themselves. The range of sensory impairments included in the term "deaf-

blindness" is great. (adapted from National Consortium Deaf-Blindness, "What is Deaf Blindness", www.nationaldb.org)

The Illinois Advisory Board for Services for Persons who are Deaf Blind (IABDB) addresses issues that arise across the lifespan of an individual with deaf-blindness. These issues may take many forms such as Early Intervention services for infants and toddlers, educational services for children and youth or aspects of adult living such as living supports, transportation supports, medical supports or advocacy. It can even involve the aging issues of our senior citizens who acquire sensory disabilities. Giving the changing demographics of our country, many Baby Boomers are experiencing the typical sensory losses associated with aging. We continue to confront the devastating consequences of war as our servicemen and women return home with grievous head injuries that may include vision/hearing difficulties.

In conclusion, deaf-blindness exists across the generational continuum and may touch persons at any stage of life. Issues affecting persons with deaf-blindness range from the availability of Early Intervention services, trained teachers in childhood, available and accessible medical, living, employment, transportation, recreation and advocacy services in adulthood. Always present are issues related to the unique communication needs of individuals who are deaf-blind, such as Braille, sign language and tactile sign though interpreters. Our Board's charge encompasses the totality of these needs.

IV. General Recommendations for Illinois Services

The Advisory Board's recommendations are as follows:

1. The General Assembly should propose and pass legislation that will give consumers and their families the ability to self-direct funds for services and make choices for services on an individualized basis much like a child's educational plan is customized for each individual child.
2. Adopt a standard definition of deaf-blindness for all state agencies and include deaf-blindness as a separate category on the state PUNS questionnaire (Prioritization of Unmet Needs).

V. Major Activities

Meeting Dates

During the FY10, The Illinois Advisory Board for Services for Persons who are Deaf-Blind convened meetings October 1, 2009, December 3, 2009, February 4, 2010, April 1, 2010, and June 3, 2010. During the FY 11, the board met on October 7, 2010, December 2, 2010, April 7, 2011 and June 2, 2011. The meetings normally scheduled for August were cancelled. Meetings are scheduled for the first Thursday of every second month.

Summary of Major Activities

1. Coordinated Illinois Deaf-Blind Awareness week 2010. IABDB has continued to work with Engage Creative to develop a media campaign for the board and to enhance the visibility of the board's website. With the assistance of Engage Creative, the board developed four profiles highlighting the unique qualities of four individual with deaf-blindness ranging from 3 to 70 years of age as well as a summary profile. In 2011, this year's Helen Keller DBAW campaign celebrated the accomplishments of one of our recently retired board members. In both years, an email blast was sent to approximately 1,200 targeted email addresses.
2. Redesigned the IABDB website, www.bemyvoice.com. We also expanded the website to include a "Call to Action" section. The website contains a wealth of information, numerous important links and resources for families and consumers. Our YouTube video may also be accessed by the site.
3. We opened a Facebook page for IABDB. This social media avenue will allow us to spread awareness about our group and link our annual deaf-blind awareness week campaign to it.
4. Served as an advisory committee for Project Reach: Illinois Deaf-Blind Services and provided input to Hearing and Vision Connections (HVC). Supported the transition of HVC to Hearing and Vision Early Intervention Outreach (HV/EIO).

VI. Closing Comments

In many of our Annual Reports we have shared our grave concerns regarding the state of services for persons with disabilities in general and with services for persons who are deaf-blind specifically. Recent events at the state level give us little hope for optimism that Illinois will rise to the challenge of shrinking resources with creative and inclusive practices for persons with disabilities including deaf-blindness in the state.

We despair when we read articles like the one recently printed in the Chicago Tribune entitled “Parents of Disabled Kids are giving up on Illinois” (Chicago Tribune, May 29, 2011). This article contends that families with children with disabilities have found Illinois services so lacking that they have moved to other states in order to ensure that their children get the services they need. This goes for families of adults with disabilities as well. According to Tony Paulauski, Executive Director of the Arc of Illinois, “(C)urrently, Illinois ranks last in the nation for supporting citizens with disabilities in their homes” (Rockford Register Star, May 27, 2011).

We do not want to give up on Illinois. We want to be partners with Illinois lawmakers to build a better, more inclusive, more effective system of supports for persons with deaf-blindness that recognizes the need for self-determination and dignity while balancing the need for fiscal responsibility. If other states can do it, we are convinced that Illinois can do it as well.

We will continue to work with state agencies, disability advocates, and disability service providers to ensure open communication regarding the unique needs and challenges facing individuals who are deaf-blind and their families. Our website, www.bemyvoice.com now includes a “call to action” section that provides the public with suggestions for actions they may take to improve the lives of persons who are deaf-blind. We encourage you, as state leaders to hear our call to action and take bold steps to improve the lives of your citizens who are deaf-blind.

VII. GOALS and OBJECTIVES FY 2011-2012

ILLINOIS ADVISORY BOARD FOR SERVICES FOR PERSONS WHO ARE DEAF-BLIND

1. To increase awareness regarding individuals who are deaf-blind as contributing members of society.

Objective 1: Plan 2010 Illinois Helen Keller Deaf-Blind Awareness Week celebration events and campaign in conjunction with Helen Keller National Center, Illinois Deaf and Hard of Hearing Commission, and Philip J. Rock Center & School/Project Reach.

Objective 2: Develop an effective on-going public relations campaign to include a “Call to Action” regarding deaf-blindness.

Objective 3: Objective 3: Maintain updated website, www.bemyvoice.com.

Objective 4: Create methodology to track outreach efforts.

2. To ensure all rights and access to health, educational and vocational services, as well as social and residential opportunities.

Objective 1: Establish and/or maintain relationships with state and federal agencies that impact the lives of persons who are deaf-blind including Human and Family Services, Illinois Deaf and Hard of Hearing Commission and The Illinois and United States Departments of Veterans Affairs.

Objective 2: Provide model language to appropriate agencies to encourage the adoption of consistent language regarding the definition of deafblindness.

Objective 3: Advocate for the addition of a separate category of “deafblind” on the PUNS questionnaire.

Objective 4: Support Illinois School for the Deaf (ISD) and Illinois School for the Visually Impaired (ISVI) as an educational option for children with hearing and/or vision loss.

3. To ensure that individuals who are deaf-blind are empowered to determine all aspects of their lives.

Objective 1: Board members will monitor state legislation through individual contacts and as a function of their professional responsibilities.

4. To ensure families, educators and support personnel are provided with the necessary training and resources to benefit all individuals who are deaf-blind.

Objective 1: Facilitate communication among agencies and support groups for persons with deafblindness such as the Illinois Association of Deafblind and the Illinois Advocates for the Deafblind.

Objective 2: Support and participate in Chicago Lighthouse deafblind awareness events.

Objective 3: Serve as the Advisory Committee for Project Reach: Illinois Deaf-Blind Services.

5. To ensure diversity of membership in the Advisory Board as representative of the varied needs of individuals who are deaf-blind.

Objective 1: Maintain communication with appropriate state officials to ensure full representation on the board.

Objective 2: Communicate with the Secretary of DHS, Division of Rehabilitation Services to post and fill the position of Deaf-blind specialist.

Objective 3: Communicate with Secretary of DHS, Division of Developmental Disabilities, to create and post a position of Deaf-blind Specialist. If a new position is not an option, then assigning an existing employee the duties of deaf-blind specialist would be reasonable.

Appendix A. Current Members of the Illinois Advisory Board for Services for Persons who are Deaf-Blind

Name of Group	Purpose	Authorized by	Status and Timeline	#/frequency of meetings	# of Members	Appointed by	Current Chair
Services for Persons Who Are Deaf-Blind [Illinois Advisory Board for]	Makes recommendations to agencies regarding deaf-blindness	Public Act 79-966 105 ILCS 5/14-11.02	Active	6 per year	11 Sitting Members	various	Laura Frankiewicz
Annual cost	Fund source	Agency Contact	Phone #				
\$5000	IDEA	Todd/Williams & Sarah Sebert	312-814-5560				

MEMBERSHIP INFORMATION

#	Name	Title	Address	Sex	Representing	Length of term	Initial Appt. Date /Date Board Member Began Attending Meetings	Current term end
1	Gail Olson	Employee Rep.	Hearing and Vision Connections 125 Webster Avenue Jacksonville IL 62650	F	Department of Human Services/Division of Developmental Disabilities	3 Years	2003	2012
2	Faith Rosenshein Young	Parent Representative	19W079 Avenue Barbizon Oak Brook IL 60523	F	Governor's Office	3 Years	2004	2012
3	Faye Manaster	Parent Rep.	8331 Kimball Skokie, IL 60076	F	Department of Children and Family Services	3 Years	2001	2004
4	Laura Frankiewicz	Employee Rep.	245 W. Exchange Suite 4 Sycamore, IL 60178	F	Illinois State Board of Education	3 Years	1992	2011
5	Catherine Klein	Deaf-Blind Consumer	1550 N. Lake Shore Dr. # 29-D Chicago, IL 60610	F	Governor's Office	3 Years	2009	2012
6	Geraldine Lawhorn	Consumer Rep.	3510 South Rhodes, #1403 Chicago, IL 60653	F	Governor's Office	3 Years	1984	2011
7	Marsha Northrup	Statewide Coordinator	Deaf Services Department 100 West Randolph Suite 6-200 Chicago, IL 60610	F	Department of Children and Family Services	3 Years	1998	2002
8	Bob Griffith	Employee Rep.	100 West Randolph Suite 5-300 Chicago, IL 60601	M	Department of Human Services/Division of Rehabilitation Services	3 Years	2009	2012
9	Roseann Slaght	Parent Rep.	5178 Hutchison Drive South Beloit, IL 61080	F	Illinois State Board of Education	3 Years	1992	2011
10	Jody Wolfe	Parent Rep.	3021 Cyprus Court Buffalo Grove, IL 60089	F	Department of Human Services/Division of Rehabilitation Services	3 Years	2009	2012

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11	Maria Roeters	Parent Rep	632 E 161 st Place So. Holland, IL 60473	F	Department of Human Services/Division of Rehabilitation Services	3 years	2009	2012
12	Shelle Hamer	Employee Rep.	201 S Evanston Arlington Heights, IL 60004	F	Illinois State Board of Education	3 Years	2011	2014
13	John Jun	Sr. Citizen Representative	117 Pioneer, LOB 622 Minooka, IL 60447	M	Governor's Office	3 Years	2011	2014

Illinois Advisory Board for Persons Who Are Deaf-Blind – Frequent Guests

#	Name	Title	Address	Sex	Representing
1	Michelle Clyne	Project Coordinator	818 DuPage Boulevard Glen Ellyn, IL 60137	F	Project Reach IL Deaf-Blind Services
2	Laura Thomas	Regional Representative	485 42 nd Avenue East Moline, IL 61244	F	Helen Keller National Center
3	Joann Rushing	Program Manager	1850 W. Roosevelt Rd. Chicago, IL 60608	F	Chicago Lighthouse for the Blind
4	John Miller	Director	1630 South 6th Street Springfield, IL 62703	M	IL Deaf and Hard of Hearing Commission

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